Received By: dkennedy

Received: 11/04/2003

2003 DRAFTING REQUEST

Bill

Wanted: As time permits			Identical to LRB:				
For: Mark Honadel (608) 266-0610			By/Representing: Chris Reader (aide)				
This file may be shown to any legislator: NO			Drafter: pkahler				
May Co	ontact:				Addl. Drafters:		
Subject	: Health	- vital statistic	es.		Extra Copies:	DAK	
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/P1			rschluet 12/17/20	03	sbasford 12/17/2003		

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FE Sent For: 01/05/2004.

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2003 DRAFTING REQUEST

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2003 DRAFTING REQUEST

Bill

Received: 11/04/2003	Received By: dkennedy
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For: Mark Honadel (608) 266-0610	By/Representing: Chris Reader (aide)
This file may be shown to any legislator: NO	Drafter: dkennedy
May Contact:	Addl. Drafters:
Subject: Health - vital statistics	Extra Copies:
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Requester's email: Rep.Honadel@legis.state.wi.us	
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Pre Topic:	
No specific pre topic given	
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Instructions:

See Attached

Drafting History:

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Certificate of birth resulting in stillbirth

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Jacketed

Required

/? dkennedy

FE Sent For:

Kennedy, Debora

From:

Reader, Chris

Sent:

Tuesday, November 04, 2003 2:38 PM

To: Subject: Kennedy, Debora RE: drafting request

That sounds good- I should be able to work around your schedule- if you can make it yet today that would be great, otherwise anytime this week should work out- just call first and I'll clear my schedule.

thanks!

----Original Message-

From:

Kennedy, Debora

Sent:

Tuesday, November 04, 2003 1:43 PM

To:

Reader, Chris

Subject:

RE: drafting request

I am free the rest of today and most of Friday. Wednesday I have a bill in the Assembly, but can probably work around that. I don't yet know Thursday's calendar.

----Original Message-----

From:

Reader, Chris

Sent:

Tuesday, November 04, 2003 1:39 PM

Kennedy, Debora Subject: drafting request

Debora,

Our office has been researching possible legislation regarding the state issuing "Certificate of birth resulting in Stillbirth" certificates to mothers of stillborn children. We are close to being ready to have the bill drafted- when would you be available to sit down and discuss the possible legislation?

Thanks!

Chris Reader

Representative Mark Honadel Wisconsin State Assembly, 21st. District Room 6 North, State Capitol P.O. Box 8952 Madison, WI 53708 (888) 534-0021 toll free (608) 266-0610

STATE OF WISCONSIN – **LEGISLATIVE REFERENCE BUREAU** – LEGAL SECTION (608–266–3561)

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Reader, Chris

From: Sent: Heavenly Angels [heavenheart1@netscape.net]

Wednesday, October 29, 2003 9:42 PM

To: Subject: rep.honadel@legis.state.wi.us Grieving Parents need your help



Untitled Attachment

October 29, 2003

Dear Representative Mark Honadel,

My name is Rebecca Lomis-Stephan and I am a resident here in Milwaukee, WI. I am writing you to share a tragic story that occurred on July 4th, 2003. I was told that you might be able to help my husband and I.

On February 8th, 2003, my husband and I conceived identical twin girls. With much neglect from doctors and misdiagnosis after another we were able to enjoy much of the pregnancy. It was exactly 14 weeks when we actually found out that we were indeed carrying twins. We were ecstatic that we would add 2 beautiful girls to our family of five.

Soon after we found out that we were carrying twins, Olivia Lynn and Abrianna Patrice, we were told by our Doctor (OB) to find ourselves a high-risk doctor. We were not consulted about having twins or anything but all were well and we started our search for a high-risk doctor.

It took us 5 weeks before we got to see a high-risk doctor at St. Joseph's Hospital. Two days after my first visit I noticed that the girls were not moving so I called my doctor and he told me that it was normal for being at 21 weeks gestation and not to worry about it. So the next day came and I insisted that something was wrong, since they were so very active. I went into the hospital and the doctor proceeded to do an ultrasound. I will never forget that moment! The doctor turned to me and said, "I'm sorry Becky, there are no heartbeats."

This moment was the longest moment in my life. I wailed so loud that the entire hospital heard my pain. My husband and our three other children were with us when the doctor was checking our sweet girls. My five-year-old looked at me and said, "Mama, they are with Jesus now!" My eight-year-old was in complete shock, and my two-year-old just cried because he could feel his Mama's pain. My husband tried to help me but he broke down in tears and held all of us.

I gave birth naturally to Olivia Lynn and Abrianna Patrice four days after we found out that they had died. After giving birth, we buried our children. Over 100 relatives and friends came to our girl's funeral.

As time went on, I wondered why I did not receive any Birth or Death Certificate. I e-mailed vital records and they stated that babies born still after 20 weeks are recorded for statistical purposes but then the records are destroyed and no certificates, birth or death, are given to the parents.

Needless to say, my husband and I were absolutely stunned and hurt that the same state that said we had to bury our children, would not give us a birth certificate, death certificate or even a stillborn certificate!

Six months of a beautiful pregnancy, feeling my girls move and have the hiccups, giving birth to them, and then burying them, and no certificate. Something was seriously wrong here!

I did much research and found the following and these are the reasons why the State of Wisconsin should pass a law that allows babies that are between 20 weeks and 40 weeks that are born still have a Stillborn Certificate,

- * 26,800 babies born each year in the United sates are born still
- * Most hospitals only deliver babies vaginally after 20 weeks gestation, which means that a stillborn baby would have to travel down the same birth canal as an alive baby would travel through.
- * Currently there are 6 states that issue stillborn certificates to grieving parents, Arizona, Indiana, Iowa, Kentucky, Massachusetts, and Utah. This certificate is called 'Certificate of Birth Resulting in Stillbirth or Certificate of Stillbirth'. This leaves our state one of the many that do not offer such a thing.
- * Finally, the term stillborn pertains to being born or birthed. It only seems quite logical that a certificate should be issued from the state of Wisconsin.

I am asking you to help us pass a bill that will allow babies who are born still receive a Stillborn Certificate. Mind you that this is not a 'Pro-Life or Pro-Choice' issue but rather a logical decision. Families need closure and this will definitely help the grieving process.

I thank you for your time and I am sure you will do all you can as our repersenative to do what is right by us grieving parents of stillborn babies.

Sincerely,

Rebecca Lomis-Stephan

4615 S. Kansas Ave.

St. Francis, WI 53235

69.01(12)

(12) "Final disposition" means the disposition of a corpse or <u>stillbirth</u> by burial, interment, entombment, cremation, delivery to a university or school under s. 157.02 (3) or delivery to a medical or dental school anatomy department under s. 157.06. "Final disposition" does not include disposition of the ashes produced by cremation of a corpse or <u>stillbirth</u>.

69.18(1)(e)1.

1. (intro.) If a death is a miscarriage and 20 weeks or more have elapsed between the mother's last normal menstrual period and delivery or the <u>stillbirth</u> weighs 350 grams or more, one of the following shall submit, within 5 days after delivery, a fetal death report to the state registrar:

69.18(1)(e)1.b.

b. If the miscarriage does not occur at or on route to a hospital, the funeral director or other person authorized by at least one parent of the **stillbirth**.

69.18(3)

(3) Requirements for disposition of a corpse or stillbirth.

69.18(3)(d)

(d) No person may remove a corpse from this state if the place of death was in this state unless the corpse is accompanied by a copy of the report for final disposition. If a medical certification is required for the corpse under sub. (2) (d), the corpse must be accompanied by the report and the written permission of the coroner or medical examiner to embalm and effect final disposition. No person may remove a <u>stillbirth</u> from this state if the delivery of the <u>stillbirth</u> was in this state unless the <u>stillbirth</u> is accompanied by a report for final disposition.

69.18(3)(e)

(e) (intro.) Except as provided under par. (d), no report under par. (a) is required to effect final disposition of a **stillbirth**. No person may effect final disposition of a **stillbirth** without the written authorization of any of the following persons, in order of priority stated, when persons in prior classes are not available at the time of authorization, and in the absence of actual notice of opposition by a member of the same or a prior class:

69.18(3)(e)1.

1. A parent of the stillbirth.

69.18(3)(e)2.

2. An adult brother or sister of the stillbirth.

69.18(3)(e)3.

3. A grandparent of the **stillbirth**.

69.18(3)(e)4.

4. Any other person authorized or under obligation to dispose of the stillbirth.

Ch. 157 - ANNOT.

Cross Reference: See s. 69.18 for 1) registration of deaths; 2) medical certification; 3) disposition of corpse or <u>stillbirth</u>; and 4) disinterment and reinterment. 767.24(7m)(a)1.

1. The known medical history of the parent providing the information, including specific information about **stillbirths** or congenital anomalies in the parent's family, and the medical histories, if known, of the parents and siblings of the parent and any sibling of the child who is a child of the parent, except that medical history information need not be provided for a sibling of the child if the parent or other person who is granted legal custody of the child also has legal custody, including joint legal custody, of that sibling.

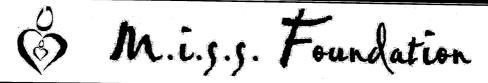
891.09 Record of births, **stillbirths**, fetal deaths, deaths and marriages. 891.09

891.09 Record of births, <u>stillbirths</u>, fetal deaths, deaths and marriages. 891.09(1)

(1) Records as evidence. The record of any marriage, birth, <u>stillbirth</u>, fetal death or death kept in the office of any register of deeds or local health officer of a local health department, as defined in s. 250.01 (4) (a) 2. or 3. or (b), or in the state bureau of vital statistics shall be received as presumptive evidence of the marriage, birth, <u>stillbirth</u>, fetal death or death so recorded.

891.09(2)

(2) Church and doctor's records. Any church, parish or baptismal record, and any record of a physician or a person authorized to solemnize marriages, in which record are preserved the facts relating to any birth, stillbirth, fetal death, marriage or death, including the names of the persons, dates, places and other material facts, may be admitted as prima facie evidence of any fact aforesaid. But such record must be produced by its proper custodian and be supported by the custodian's oath that it is such a record as it purports to be and is genuine to the best of the custodian's knowledge and belief.



"MISS Foundation's Legislative Reference Site"

About the MISS Foundation | Bereaved Children | Family Support | For Professionals The Kindness Project | The MISS Store | Group Locator | Baby's Breath Program Forums | Upcoming Events | News | En Espanol | Donate

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The Politics of Stillbirth & The MISSing Angels Bill Meeting With Your Legislators: Helpful Hints

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STATE CHART: Which States Issue the C.B.R.S.?

Arizona's MISSing Angels Bill: On the Internet – in all of its forms Arizona Vital Records Notice of Substantive Policy Statement Hospital Compliance Letter & Communication Strategy

> A Nationwide Petition Find Out Who Represents You!

News Article Index (Coming Soon!)

Participate in a Research Study (Coming Soon!)

A Message from Joanne, July 15, 2003

Date:

July 15th 2003

From: Subject:

Joanne Cacciatore-Garard, Founder, The M.I.S.S. Foundation "S-t-i-l-b-i-r-t-h..., For all mothers of stillborn infants"

For Mothers AND Fathers, too:

Proloque

From my heart and with utmost sincerity, I believe that the death of a child at any age and

from any cause is unbelievably overwhelming. What I am about to say about stillbirth is not meant to focus on the event of stillbirth, but rather, on the historically pervasive attitudes about the death of a baby just prior to or during birth.

The Problem

For decades, all other types and causes of child death have achieved respect, research funding, and programs and at the very least, are recognized as "child death" in the arena of public health departments, legislation, and research. Until very recently, and not without many battles- some wars, stillbirth has been ignored in every public health arena in the country.

There are no "stillbirth" task forces or Stillbirth Advisory Councils or Stillbirth Reduction Committees. Nothing. Up until Cheyenne's death, I had never even heard a story on our local news about stillborn infants...I never knew that a woman could really lose her baby at the end of her pregnancy for no identifiable cause~ I didn't know that in 1994, so few really even cared. Stillbirths aren't even counted in any data on child death. Shame on society.

Every news person I'd ever done an interview with admitted they'd never done a story on it, that Cheyenne's photo was the first of a stillborn baby's photo they'd seen, and never realized the breadth and width of the problem.

A new media trend is emerging. National media attention has been given to MISS and other groups fighting for stillbirth and supporting stillbirth families...we've gotten the MISSing Angels Bill passed in 11 states and we're committed to all 50 by 2007. Arizona now has a formalized advisory council to examine stillbirths the same way that they've had one to examine other infant deaths. Many of our MISS chapters have been in their local news and now, even Rap singers are talking about stillbirth!

This is a very, very important time in history. One that will go down in public health records and legislative manuals.

History

Stillbirth, for decades, has been overlooked and disregarded as the number one mechanism for child death. Estimates range from 25,000 to 39,000 stillbirths annually in the U.S. That is approximately 83 per day or 4 per hour. Stillbirth takes the lives of more infants than all other causes of deaths COMBINED!

Yet, public health officials, research universities, and the media have ignored stillbirth despite these outrageous numbers. If you hear about "infant mortality" rates in your state or in the U.S., they do NOT include stillbirth rates...you see, stillborn babies are NOT considered infants- or children- or human for that matter. Not in the eyes of public health. This attitude has been the driving force of the complacency toward stillbirth in society.

Our Future

While the situation is changing, much work remains. Before the day that I die, stillborn infants and the women who endure the horror of giving death to their baby instead of life will get some respect. These children, of whom 50% die for no diagnosable reason, are worthy of research dollars to determine why and to reduce the numbers. Maternal health is of value in our country. Our ongoing trend to ignore it is no longer tolerable.

Stillbirth is out of the closet. And I will fight until my last dying breath to make sure it stays that way. All our children matter and all our children deserve to be treated with dignity, respect, and equality.

The time has come. Watch it carefully. If you're interested, get involved~ email me~ we

have a task for you. It is our voices which will compel change \sim the voices that we use to speak for our children.

Because she lived and died within me,

Joanne Cacciatore-Garard Mother of Cheyenne MISS Founder Warrior for Her

Back to Top

What is a MISSing Angels Bill?

Let's first focus on the last word (bill) and then work our way to the 'beginning'...

It all started with an idea that a change needed to happen. When 'ideas' are introduced into the realm of a state's legislative body, ideas often become Bills. The definition of a **Bill** is 'a draft of a law presented to a legislature for enactment'. Sometimes, an originating bill is also known as the law that evolves from it (as in the 'G.I. Bill'). If all goes well, a Bill becomes an Act (the formal product of a legislative body), then the Act becomes a Statute (a law enacted by the legislative branch of a government).

And now, to the 'MISSing Angels' part of it:

On July 27th, 1994, Joanne Cacciatore-Garard's precious daughter Cheyenne was born still. Joanne received no birth certificate from Arizona acknowledging her 'motherhood,' nor the birth of Cheyenne, and felt this to be wrong. She wrote her legislator and asked that a change be made - and thankfully - she didn't stop there. Since Cheyenne's death, Joanne founded a group for parents who lose infants called M.I.S.S. (Mothers In Sympathy and Support). Joanne dedicated more than a year of her life in Arizona's Senate and House chambers meeting with legislators, public health officials, and organizing a task force in 1999 with volunteer members including Paula Mikkelson, Heidi and Carl Brashears, Kipp and Susie Charlton, Guillermo Gutierrez, M.D., David Garard, Sgt. Randy Force, Dr. Mark Fischione, and Cindi Nannetti. M.I.S.S. Foundation's families were the initiators and supporters of this legislation.

A portion of the text in the original legislation reads: Section 36-329.01, Arizona Revised Statutes, as added by this act, may be cited as the "Missing Angels Act".

The actual name of the legislation was meant to be 'MISSing Angels' in order to honor the M.I.S.S. Foundation families and Cheyenne Cacciatore for whom the organization was originally founded. Due to an administrative error, however, the legislation was formally documented in an incorrect manner.

Back to Top

HB2416 - Certificates of Birth resulting in Stillbirth

About this important piece of legislation

What is the definition of "stillbirth?"

A stillbirth is an intrauterine death that can occur after the 20th week of pregnancy all the way up to birth. The "stillborn infant" is born without any attempt at respiration, including a beating umbilical cord. Even a post-term baby who dies one minute prior to birth is considered a stillborn.

What is the current protocol in Arizona for stillbirth?

The registrar of vital records issues a "Certificate of Fetal Death" for all stillbirths. This is the only record the family is able to receive at this time.

How many stillbirths occur in Arizona every year? How many in the nation? According to the DHS website, in 1999 there were 682 stillbirths. In the United States, there are approximately 30,000-39,000 stillborn babies every year. Actual numbers are unknown which is one reason why this bill is necessary.

What is the proposed change in HB2416?

This change would require vital statistics to issue a "Certificate of Birth, Resulting in Stillbirth" for each stillbirth (which, by definition, excludes all abortions).

What are the benefits of HB2416?

- 1.Standardized statistical benefits: Issuing these certificates for stillbirths would allow clear definitions for accurate statistical analysis and enhanced understanding of stillbirth. It will allow for better clarity in classification.
- 2. Reduced insensitivity to women who endure the death and the birth of their stillborn infant. Many women express strong feelings of disenfranchisement merely because their child was born dead. The state's refusal to validate the experience of childbirth is inexcusable. Simply offering a death certificate, a constant reminder of a woman's perceived failure, is unjustifiable. A mother of a stillborn must still give birth to her dead infant.
- 3. Consistency in the law: Currently, the family of the stillborn infant is required to carry the duty to bury the stillborn child. Yet, there is no willingness to acknowledge that this infant ever "was."
- 4. Equitable Treatment: A premature infant born at 21 weeks gestation weighing less than? Ib, that takes one small breath, yet has no chance at survival outside the womb will receive a "Certificate of Live Birth." Conversely, a baby born at 42 weeks gestation that dies minutes prior to birth, and weighs 10 lbs will be viewed as a "fetus." This is very inconsistent and difficult for the family of the full term infant to accept. There is no additional ongoing cost to the state for this proposed legislation.

HB2416 is the right thing to do.

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"What you should know about the 'Politics of Stillbirth & The MISSing Angels Bill"

© 2003 MISS Foundation

Q: I want to know how to get "Certificates of Birth Resulting in Stillbirth" in my state. Where do I start?

Start by reviewing the MISS Foundation's Legislation Information page regarding the MISSing Angels Bill. Once you've reviewed this, please email our volunteer national legislative liaison, John Nevels. We'll connect you with others in your area and/or get you the information you need to help initiate this movement in your state.

Q: My state's legislative website has a page on how a bill is passed – but it seems really difficult – is it that way everywhere?

It is certainly a time-consuming process, however, even those without any previous lobbying or political experiences can accomplish it. Some of the most meaningful changes in public policy have come from grass-roots efforts. One thing that will help is the ability to connect with others in your area. This balances the workload. The MISS Foundation will help you make those very important and helpful connections.

Q: Can you give me a "step-by-step generic outline" to getting this done? Is there such a thing? I work full time - how involved do I really have to be in order to get this done?

The first 'step' is for you to research the background of this legislation and know both sides of the (potential) argument. The next step is to know who your legislators are for your neighborhood. Once you are familiar with the 'issues,' you should email us for further guidance. We strongly recommend the support of a Democrat sponsor. This will often reduce the amount of ongoing work and communication that will have to come from outside the legislature. Once you find a legislator to author the bill, much of the work can be accomplished from a distance, meaning emails, letters, and phone calls. Some states, due to political atmosphere, will require more of a time commitment.

Q: I understand that I need to write a letter to my Representative and/or my Senator – but I'm curious – do I have to write the one who represents me in my district – or can I pick and choose?

You should consider several issues. First, are you a constituent? Second, are they a democrat, republican, or independent? Generally, we recommend that the bill's primary author be from the democrat or independent party in states where the political atmosphere is tense.

Q: Wouldn't it be better to just send my letter to every legislator in my state and hope for the best?

We do not recommend this strategy. Although it can work in some areas, the author of the bill has a direct effect on the amount of work you'll have to do and the degree of opposition the bill will have from other groups with an interest in this issue.

Q: What do I need to say in my letter? Is there anything I shouldn't say?

Tell your story as a stillbirth parent. There is a sample letter on the website that you can review and use as a template. We strongly recommend that you do not use any language about "fetal rights" or other vernacular which may stir up discussion about the politics of abortion. Stillbirth and abortion are separate and distinct and mutually exclusive events.

Q: Do I really have to meet with my legislator(s)? I'm not very good with meeting "official people". I may not have the time - isn't enough just to write a letter of support if someone else is already doing all the other stuff?

If you're not comfortable meeting with your legislator, then we recommend that you find others in your area who are willing to help. Face-to-face meetings and the presence of supporters in committee hearings are critical to the success of this legislation in most states.

Q: I've noticed in a lot of letters where people are quoting their state's statistics. Do I really need to know what the statistics are in my state – and if so – where do I find something like that?

Yes. Statistics are a powerful and effective tool which demonstrates the magnitude of the stillbirth problem in America. You can search the cdc.gov website for more information or your state's vital records office online. If you're having trouble locating this information, please let us know.

Q: What are the nationwide statistics for stillbirth – and how come they change so dramatically according to whomever is giving them out?

Rates vary due to the inaccurate documentation and the lack of specific state reporting protocol. Estimates range from 26,000-39,000 stillbirths per year in the U.S. We are hoping that this legislation will encourage better and more accurate statistics.

Q: How can I possibly find a legislator in my state that is sympathetic to this?

Our suggestion is that you should read about your legislator on your state's website. Their biography may help direct you. Key legislators would be on the Health and Human Services Committees, however, this is not required.

Q: Everyone who I talk to about this seems to want to bring "abortion" into this issue – what's up with that? Why do they do that – and how can I get them to understand that "abortion" isn't what it's all about?

The arena of women's rights and the protection of them thereof, precipitate painful verbal and political battles between legislative parties. It is very important to be clear when discussing with legislators that your personal opinion on abortion has no influence on this issue. Stillbirth is the death of a child as a result of natural causes. By definition, stillbirth excludes induced abortion. We recommend that you do not state your personal opinion in any meeting and that you refrain from using any type of abortion, either for or against, rhetoric in your meetings and letters.

Q: Someone's already doing this in my state – but they belong to that "other organization", I want to help – but I'm afraid. What can I do?

This bill is so important that we will work with others at any expense. However, if at any point you are uncomfortable, it is still possible to support this legislation in absence of a cooperative working relationship with other groups.

Q: What is a "National Legislation Liaison" anyway? How is this person supposed to help me?

The NLL is a volunteer-based guidance position. John Nevels will help guide you and help you find information that you will need to be successful. We may not have all the answers,

however, we're here to help you and to connect you with others. The NLL will ensure accurate information is being disseminated and will provide the support you'll need.

Q: I understand that my state already does this – but not by law. What's the big deal anyway? As long as I can get a certificate – I'm happy.

When a state issues the Certificate of Birth Resulting in Stillbirth by policy and not law, this means that it can change at any time and with great ease. A simple change in staff, ideology, or budget could initiate such a change. We believe that this legislation is so important that each state must have a law to ensure consistent and accurate data on stillbirths and to ensure respect of current and future families experiencing stillbirth.

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Meeting with your legislators: A few helpful hints for new political activists!

"...and though they cannot speak, they do speak, still. For we are the voices of the children who cannot speak for themselves. We do it for them, in their honor and on their behalf. We will not stop until justice has been done." Joanne Cacciatore-Garard, Founder, M.I.S.S.

- 1. Your first step is to find out who your local senator and representatives are. You can find that out by going to this {link}. Ensure that you know your district because when you call your legislator, you will be a constituent. Constituents are very important to legislators. Find your State Senator.
- 2. Call your legislator's office and set up an appointment to meet for 20 minutes. Tell them that you are a constituent in his or her district.

HELPFUL HINTS

- 1. Write a letter to your senator, representative, and/or assemblyman. Tell them you are a constituent, to please read the letter carefully, and that you will follow up in one week with an appointment.
- 2. Make an appointment with legislator's staff. Tell them you have already sent a letter (you stand a better chance if you are a constituent) and would like to meet with them.
- 3. Dress professional and present yourself as a concerned citizen, not just for yourself but for your community members as well.
- 4. Plan your visit carefully! Be clear about the facts and try to be direct. Know your members and their "issues" before meeting with them.
- 5. Be prompt and patient!
- 6. Be prepared! Print pages from the M.I.S.S.ing Angels Bill page and read through the history and impetus for the bill. Know your national and state statistics (we can help you with that!) and bring the HB2416 information sheet with you.
- 7. Be political! Demonstrate the connection between this bill and the interests of their

constituents. Ask for a commitment.

- 8. Be responsive and follow up. Send a thank you letter outlining their discussion and commitment and send along any follow up information they may have requested.
- 9. Ask them for a bill number and email the MISS Foundation office immediately so we can begin to assist you in getting support.

Source: The Washington Times, Revised Congress Journal 3, adapted by the MISS Foundation.

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Letter Joanne sent to her legislator, Senator Mary Hartley

Joanne Cacciatore P.O. Box 5333 Peoria, Arizona 85385

623.979.1000

www.missfoundation.org

Senator Mary Hartley Arizona Senate 1700 West Washington Phoenix, Arizona 85007

RE: MISSing Angels Bill

April 20, 1999

Dear Senator Hartley,

With great respect and as a registered voter I feel compelled to write to you regarding an issue that is very important to me. I write speaking for many families in your home state and nationwide. I hope that because of this, you will be prompted to take a little time and please consider what I am about to share with you.

I am writing to tell you about my daughter, Cheyenne Cacciatore. When I first discovered I was pregnant, you can imagine how happy our family was. However, on July 27, 1994, what was supposed to be one of the happiest events of our lives, became the most devastating. During the excruciating pain of labor, my daughter died at 40 weeks gestation, 15 minutes prior to birth. The cause of her death was undetermined. The medical term for this is stillbirth, although she died from S.A.D. Syndrome. This is similar to SIDS, however, it occurs just prior to birth, and it too results in no answers during the postmortem evaluation. I never drank alcohol, did not smoke, and did everything 'right.'

The statistics are shocking for this type of death. There are more than 35,000 babies 'stillborn' in the U.S. every year. In just our state, there are approximately 700 every year.

Since her death, I founded a group for parents who lose infants called M.I.S.S. Our website receives more than 55,000 visitors a year. I also volunteer for the Compassionate Friends, and volunteer for the Crisis Center. In 1996, I began the first grief protocol in our state addressing death and ethics for professionals. I have taught this seminar at more than 500 facilities across the state of Arizona. I also wrote a book about the death of my baby girl called "Dear Cheyenne." I also began the Kindness Project© in 1997 and was a featured guest on the national talk show, "Leeza Gibbons," sharing my experience with Cheyenne's death.

I am requesting your assistance on supporting an issue critical to thousands of Arizona families. In 1994 after Cheyenne's death, I was awaiting her birth certificate for her baby book. One of the most disenfranchising problems with 'fetal' death, or early neonatal death is the lack of tangible memories with the child- thus any memento of the child's existence is critical in the healing process. Instead, two weeks after Cheyenne's death, I received a "Certificate of Fetal Death." I waited ten long months, endured natural childbirth, delivered an eight-pound, 21" long baby, and still had milk in my breasts for a child whom I buried one week earlier. Yet I received no birth certificate from the state acknowledging my 'motherhood,' nor the birth of this child.

I am asking you to support a bill bynamed the MISSing Angels Bill. It would require a simple change from "Certificate of Fetal Death" to "Certificate of Birth resulting in Stillbirth."

On behalf of thousands of families in our MISS group, I ask you to help us in changing our current protocol. Their births are no different than any other except their parents must leave the hospital without their child. Mothers of stillborn babies must still give birth. For them, the immeasurable physical pain and trauma of childbirth is coupled with the most emotionally traumatic - death.

It is an event that deserves far more respect than it receives.

It is my hope that not only will Arizona meet the needs of parents who suffer such a devastating loss, but also serve as the forerunner for other states to do the same. Perhaps one day the state will deem in appropriate to acknowledge my daughter Cheyenne, and the fact that she lived, she died, and that- even in death, she very much matters.

If it is acceptable to you, I shall contact your office for an appointment to meet with you regarding this, or if you have any further questions prior, you may contact me at the above number. For all you do to help Arizona families, and,

In appreciation of your consideration-

Respectfully,

Joanne Cacciatore-Garard, RTS Counselor

M.I.S.S. National-Arizona Chapter

Mother of four who walk, and one who soars

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Joanne's testimony notes before the Senate Health Committee.

Greetings Mr. Chairman and Health Committee Members,

My name is Joanne Cacciatore-Garard. I come to you today in hopes of securing your support for an very important piece of legislation for women and their families.

In 1892, American Author and Philosopher, Mark Twain said, "Favored above Kings and Emperors is the stillborn child." I wish that stillbirth and the experience of having to deliver a dead baby was respected in this manner back in 1994 when my fullterm baby girl died during childbirth.

(I told my personal experience with Cheyenne's death here)

This tragedy strikes everywhere. According to the Center for Positive Outcomes in Pregnancy in Washington DC, there are 39K stillbirths in the US every year. In 1999, there were more than 600 in Arizona. This has affected our neighbors, my husband's friends within the fire dept, even your fellow legislators. Historically, we share this horrific experience with John Quincy Adams, Rutherford Hayes, Ernest and Pauline Hemingway, and John and Jackie Kennedy, whose stillborn daughter is buried with her parents and siblings.

Dr. John DeFrain of the Univ of Nebraska did an intensive research study of stillbirth in the early 80's. Many of the hundreds of participants expressed deep pain and anxiety about the lack of validation for the experience of birth. I asked myself while re-reading this study the other day, "Why didn't they do anything about it then?"

I don't know. But here I stand before you today, asking you to make this right.

Childbirth is a unique physiological experience for women. It is such an important event that we celebrate it every year in a ritual called the 'birthday.' Suzanne Arms, internationally acclaimed author and photojournalist said of childbirth: Birth is an inherently successful process that is a major social, economic, political, spiritual, and environmental issue.

Ask any woman why she would endure the pain and agony of giving birth and she will tell you because of the 'reward' at the end...it is 'all worth it,' we frequently hear. But what about the silent births- the women who get no reward for all their hard work...

Arizona, as all other states in the US, currently issues the "Certificate of Fetal Death" for stillborn infants. This document is a cruel and oppressive reminder of a woman's failure to produce a healthy living baby. Women who endure stillbirth must still give birth- a physiological process that includes great physical pain, incalculable emotional investment, postpartum symptomology, and financial sacrifice.

We are asking you to change this. Women deserve a birth certificate for their babies. Other countries such as Australia, New Zealand, Norway, Canada, and Ireland currently issue birth certificates for stillborns. It is time for the United States to join these countries in their support of women.

HB2416 is the right thing to do for Arizona women and their families. It is a change long overdue. We cannot issue merely a death certificate to the women who give birth to stillborns. The birth, too, must be acknowledged in a compassionate and sympathetic way. This is the right and just thing to do. And as Martin Luther King, Jr. said, "It is always the right time to do the right thing."

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"Transcript: Arizona's Last Public Hearing on House Bill 2416"

ARIZONA STATE SENATE 45TH LEGISLATURE

MINUTES OF COMMITTEE ON HEALTH

DATE: March 20, 2001

TIME: 1:30 p.m.

ROOM: SHR 2

CHAIRMAN: Senator Gerard

VICE CHAIRMAN: Senator Nichols

ANALYST: Jason Bezozo

COMMITTEE SECRETARY: Carol

Dager

INTERN: Meghann Brennan

ASSISTANT ANALYST: Kathy

Seeglitz

ATTENDANCE

BILLS

Committee Members	Pr Ab	Ex	Bill Number	Disposition
Senator Cirillo	Χ		HB 2238	DPA
Senator Guenther		Χ	HB 2245	PD
Senator Hartley	Χ		HB 2412	DISCUSSION/HELD
Senator Hellon	Χ		HB 2416	DP
Senator Solomon	Χ		HB 2629	DISCUSSION/HELD
Senator Verkamp		Χ	HCM 2003	DP
Senator Nichols, Vice Chairman	Χ			•
Senator Gerard, Chairman	X			

Chairman Gerard called the meeting to order at 1:45 p.m., and attendance was taken.

Attendees Sign-In Sheet (Attachment A)

CONSIDERATION OF BILLS

HB 2416 -Certificates of Stillbirth - DO PASS

Meghann Brennan, Senate Health Committee Intern, explained that HB 2416 requires the registrar of vital statistics to establish a certificate of birth resulting in stillbirth for each fetal death occurring after 20 weeks of gestation.

Joanne Cacciatore, citizen, quoted from Mark Twain in 1892 "favored above kings and emperors is the stillborn child." She said that she wished that stillbirth was respected in this

manner in 1994. She explained that her fourth daughter died during childbirth, full term, on her due date. There was no explanation for her cause of death. There was a post mortem evaluation and no one could give her any answers about why the baby died. She was 8 pounds and more that 21 inches long. She said that her milk came in a week after she buried her baby and for ten months she had milk in her breasts to feed a child who had died. Approximately two weeks after her death, she was waiting for her birth certificate to arrive to put in her baby book as she had done with her previous three children. She said that when she opened the envelope that came from the vital statistics office it said certificate of fetal death. She stated that she was taken aback by it and did not want to include that in her book. She said that she called the vital statistics office to find out when she would be receiving the birth certificate, the commented to her was "you did not have a baby, so you do not get a birth certificate." She stressed that she did in fact give birth to a baby.

Ms. Cacciatore related that in 1999 there were more than 600 families who endured this tragedy in Arizona, with approximately 39,000 in the United States each year. This affected everyone in her family and friends. Historically, they share this tragedy with several presidents, John Quincy Adams, Rutherford Hayes, John F. Kennedy, as well as the Hemmingways. She noted that a sociologist with the University of Nebraska did an intensive study of this during the early 1980s, researching 500 families asking them questions about their experience. They all said that it is horrible not having any validation such as a birth certificate after having given birth. This is a long overdue change that is needed. She emphasized that women who endure nine or ten months of pregnancy and the difficulty of childbirth because of the reward at the end. However, with a stillborn baby there is no reward. Further, the fetal death certificate is a cruel and impressive reminder of a woman's body's failure to produce what it is suppose to. Other countries such as Australia, New Zealand, Norway, Canada, and Ireland currently issue certificate of births for children who are stillborn. She said that she believes that HB 2416 is the right thing to do for Arizona women and their families. It is a long overdue change. She quoted from Martin Luther King, "It is always the right time to do the right thing."

Senator Cirillo moved HB 2416 be returned with a **DO PASS** recommendation. The motion **CARRIED** with a roll call vote of 6-0-1. (Attachment 1) Chairman Gerard noted the following were present in support of the bill: **Karen Wondra, citizen; Paula Mikkelson, citizen; Delynn Jones, citizen; Timothy J. Dougherty, citizen; Nicole Dougherty, citizen; and Tammy Harmonte, citizen.**

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MISSing Angels Bill Press Release

FOR IMMEDIATE RELEASE

CONTACT: Joanne Cacciatore(623) 979-1000

Re: MISSing Angels Bill signed into law by Gov. Jane Dee Hull

Phoenix, Ariz. --- With the recent unanimous passage of a bill in its Senate, Arizona has become the first state in the nation to take a positive step in changing the way stillbirths are viewed. The MISSing Angels Bill (HB 2416) will be signed into law by Gov. Jane Dee Hull in a public ceremony set for 11:25 a.m. June 11, 2001 at 1700 West Washington on the 9th Floor of the Governor's office.

The new law mandates that, instead of being issued a "Certificate of Fetal Death" upon delivering a stillborn baby, the mother will receive a "Certificate of Birth Resulting in Stillbirth."

The change might not seem significant to many. However, those who have experienced the anguish of losing a baby – whether at 30 weeks gestation or full-term – can vouch that HB

2416 is an important step allowing grieving parents the same respect given to the woman leaving the hospital with a healthy infant in her arms.

"The 'Certificate of Fetal Death' was a cruel and oppressive reminder of a woman's failure to produce a healthy, living baby," said Joanne Cacciatore, executive director of the MISS Foundation and champion of the bill. "Women who endure the experience of stillbirth must still go through childbirth. They are emotionally invested in their babies, and that does not change when a baby is stillborn. They still are mothers. The passage of this bill is a huge step in the right direction."

Sen. Sue Gerard (R-Dist. 18), chair of the Senate Health Committee, agreed.

"The passage of this bill will give much-needed respect to those who have experienced the stillbirth of a child," Gerard noted. "It may even be the first step toward increased knowledge about the causes of stillbirth. In addition, in makes Arizona the first state in what hopefully will be a national trend toward recognizing the significance of this tragedy."

Already, Massachusetts and Iowa have similar bills in place in their state legislatures, and supporters in Michigan, Florida, and Indiana also are pushing for legislation.

Approximately 39,000 babies are stillborn each year in the United States. The cause of death for more than half the number of full-term (40-week) stillbirths is unknown, even after autopsy.

Cacciatore expects many of the bill's lobbyists – a coalition of community professionals and parents of stillborn babies – will be present at the public signing.

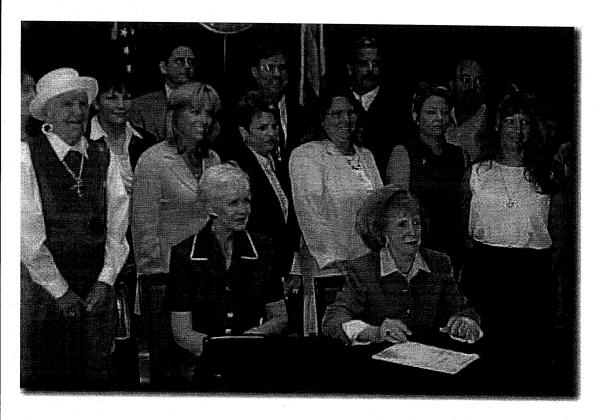
"It is a huge victory for all of us who have experienced this tragedy," Cacciatore said. "The issuance of this certificate and the public awareness it brings certainly will have implications on the statistical, medical, social and psychological effects of giving birth to a dead baby. "As Martin Luther King Jr. said, 'It is always the right time to do the right thing.' This is the right thing, and it is a change long overdue."

-30

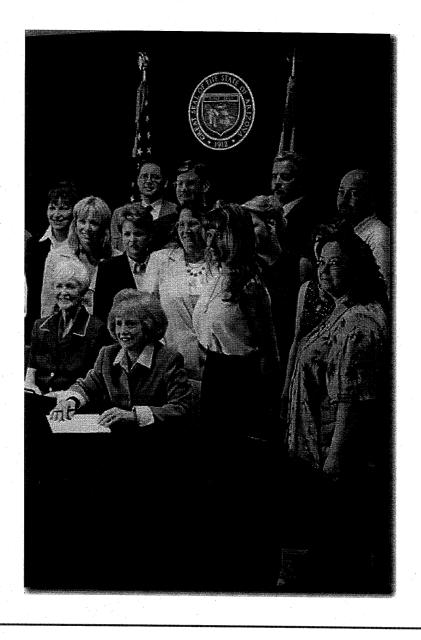
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The Photos of the Bill Signing

These photos are from the public signing ceremony held June 11, 2001.

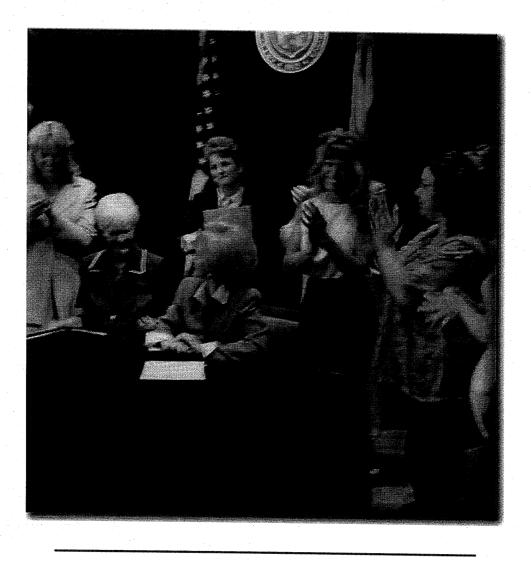


Attending the public signing ceremony held June 11, 2001 in the Office of the Governor were (from left front) Rep. Marilyn Jarrett, Governor Jane D. Hull, Joanne Cacciatore, Debbie Vinette, Millie Lawton, grandmother of Camille Rayana Olsen, Cindi Nannetti, Paula Mikkelson, Doreen Sexton, Heidi Brashears, Karen Wondra, Jami Garrison, (2nd row) Marilyn Caskey, Robin Kennedy, Sharon Olsen, Dean Synan, David Garard, Carl Brashears, Senator Mark Anderson, Tammy Haimovitz, and (not pictured) Randy Force, Richard Olsen, and Tim Dougherty.



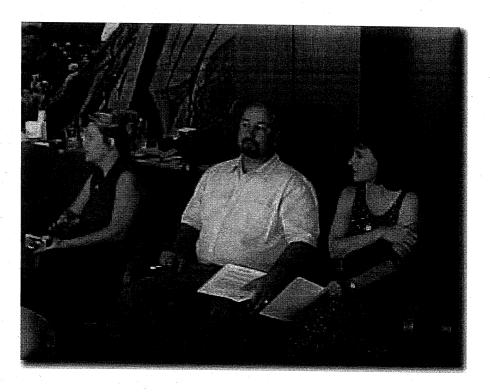


Millie Lawton and Governor Jane Dee Hull

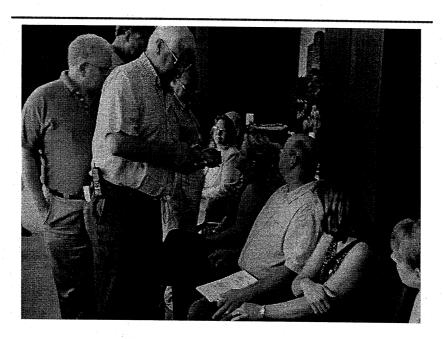




M.I.S.S. Foundation FounderJoanne Cacciatore-Garard speaking with reporters after the signing of The M.I.S.S.ing Angels Bill (Her husband Captain David Garard is behind her.)



Carl and Heidi Brashears and Karen Wondra at the signing of The M.I.S.S.ing Angels Bill.



Carl and Heidi Brashears speaking with reporters after the signing of The M.I.S.S.ing Angels Bill.

With the simple words, "We all know this change should have happened a long time ago," Arizona Governor Jane D. Hull picked up her pen and signed 'The MISSing Angels Bill', HB 2416, into law. It became effective on August 9, 2001.

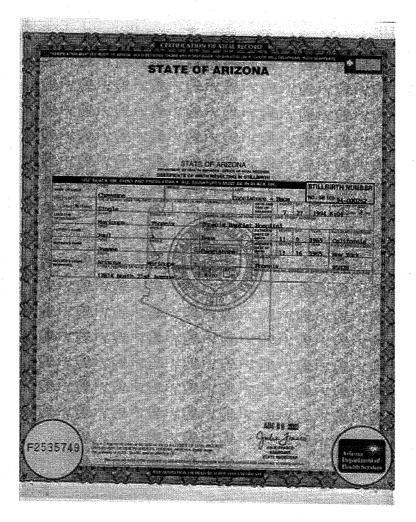
The term, MISSing Angels, references all stillborn infants, many of whom die just prior to birth or at term," explained Joanne Cacciatore, founder and director of the MISS Foundation, which championed the bill.

Arizona legislators worked with supporters of this change to draft and then enact the Missing Angels bill. The bill provides for the issuance of a "Certificate of Birth Resulting in Still Birth." No other state in the U.S. issued a birth certificate for stillborns despite the fact that the mother did "give birth." Arizona was the first. An example of the importance the legislature placed on this issue is the fact the Senate passed it on a unanimous 30 – 0 vote.

State Senator Andy Nichols, who was a steadfast supporter of the bill, died unexpectedly in May. "His presence at the ceremony was missed," said founder, Joanne Cacciatore, "I will always remember him with fondness for his tremendous compassion and love for humanity."

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The First 'CERTIFICATE OF BIRTH RESULTING IN STILLBIRTH' in the United States



To view information on how to get Arizona's Certificate of Birth Resulting in Stillbirth please, click Here.

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"MISSing Angels Legislation - A State Chart"

This chart recaps the status of the MISSing Angels Bill in every state. It provides:

- 1. A direct link to each state's legislative website,
- 2. The status of the MISSing Angels Bill in each state,
- 3. A link to the actual existing Bill or pending legislation for a particular state, and
- 4. Email links to members of The M.I.S.S. Foundation.

For states that already have the Bill, the members listed can tell you how to get a certificate for your baby.

For states that don't yet have a Bill, the members listed can tell you how to help pass the Bill in your state.

If there are no members listed for your state, and you'd like to champion for it, please email Joanne Cacciatore-Garard at joanne@missfoundation.org or call (623) 979-1000.

At present, the $\underline{\text{majority}}$ of the States in our country $\underline{\text{do not}}$ offer a "Certificate of Birth Resulting in Stillbirth".

IMPORTANT NOTE:

Although they are both worded very similarly, a "Certificate of Birth Resulting in Stillbirth" and a "Certificate of Stillbirth" are <u>not</u> the same thing.

Legislators, Policy Analysts, and State Health Departments agree, there is a subtle, yet immense difference in the two.

The M.I.S.S. Foundation believes that all states should record births as births... whether live or still.

Thus, our goal, for those states that offer a "Certificate of Stillbirth", is to change the certificate to a "Certificate of Birth Resulting in Stillbirth" which we view as a "BIRTH" certificate.

States on the chart below that have a shaded background $\underline{\mathbf{do}}$ offer a "Certificate of Birth Resulting in Stillbirth".

States on the chart below that are followed by an asterisk (*) offer a "Certificate of Stillbirth".

State:	LAW, Policy, or In Process:	Link to Bill:	MISS Foundation Contact(s):
Alabama			Stormy Entrekin
Alaska			
Arizona	LAW enacted 8-9-2001	HB2416	Joanne Cacciatore-Garard

Arkansas		z.			
California	In Process	First Attempt (AB1929) Withdrawn	Katie Hodge, Kim St. Laurent, Nadine Benton, Kim Lotz, Adrene Despars		
Colorado			Caprice Bass, Leslie Clemenson		
Connecticut			Heather Farrier		
Delaware	In Process		Tara Jones		
Florida	In Process / Died in Committee.	S 0710	Debbie Cantor, Vivienne Treharne		
Georgia					
Hawaii			Abi		
Idaho (*)	LAW Unknown Eff. Date	Idaho Statute	Nancy Grayson		
Illinois	LAW effective 8-21-2003	SB1649	Mary Geitz		
Indiana	LAW enacted 7-1-2002	Senate Bill 149	Lorri Jacobs		
Iowa (*)	By policy - not by law.		Laura Mikota, Jaye Zessar		
Kansas			Margaret Stiner, Pat Flynn		
Kentucky (*)	By policy - not by law.		Kelly Nicholls		
Louisiana	LAW effective 8-15-2003	HB918	Michele Detillier		
Maine					
Maryland	LAW effective 6-1-2003	HB 272	Jackie Nell		
Massachusetts	LAW enacted 8-10-2002	Senate Bill 453	Lynne Barberian		
Michigan	LAW enacted 10-10-2002	Senate Bill 1323	Michelle Baird		
Minnesota	In Process	SF0191	Kelly Roddy		
Mississippi	In Process / Died in Committee.	House Bill 39	Michele Rodriquez		
Missouri	In Process	SB 0435	Gregg Carder		

Montana				
Nebraska	In Process			
Nevada			Kathy Evans, Jennie Faith Chuck Baca	
New Hampshire				
New Jersey	In Process / In Committee.	S1771		
New Mexico				
New York	In Process	A04717	Jennine Jo Shull, Theresa Jankowski	
North Carolina			Anne	
North Dakota				
Ohio	In Process		Kym Smith	
Oklahoma	In Process		Pat Flynn	
Oregon	In Process	Senate Bill 660	Tracy Thomas, Wendy Nastiuk	
Pennsylvania	In Process	House Bill 799	Kim Kashar, Lisa Maloney	
Rhode Island			Anna Laye Brooke Helton Marilyn Caskey, John & Carolyn Nevels	
South Carolina	In Process	Н. 3528		
South Dakota				
Tennessee				
Texas	In Process			
Utah	LAW enacted 4-16-2002	Senate Bill 45	Ginnie Shutt	
Vermont				
Virginia	LAW effective 7-1-2003	HB 1450	Tara Pitts	
Washington	In Process		Kara L.C. Jones	
West Virginia				
Wisconsin			Rebecca Lomis-Stephan Jennifer Atkinson	
Wyoming				

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Arizona's MISSing Angels Bill: On the Internet - in all of its forms

	Document Name	Format	Document Type
	Bill Status	HTML	Bill Status Overview
	Bill Status	TEXT	Bill Status Overview
	Introduced Version	PDF	Bill Version
	Introduced Version	HTML	Bill Version
	House Engrossed Version	PDF	Bill Version
,	House Engrossed Version	HTML	Bill Version
	HOUSE SUMMARY: 1/19/01 Health	HTML	Bill Summary
	HOUSE SUMMARY: 1/24/01 CaucusCOW	HTML	Bill Summary
	HOUSE SUMMARY: 2/14/01 AsPassedtheHouse	HTML	Bill Summary
	HOUSE SUMMARY: 5/8/01 As Transmitted to Governor	HTML	Bill Summary
	SENATE FACT SHEET: For Committee	HTML	Bill Summary
	HOUSE ADOPTED AMENDMENT: Health	HTML	Adopted Amendment
	SENATE PROPOSED AMENDMENT: Health	HTML	Proposed Amendment

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Arizona Vital Records Notice of Substantive Policy Statement

The Arizona Vital Records Notice of Substantive Policy Statement is available in Adobe Acrobat's .pdf format by clicking **here**.

You will need Adobe Acrobat Reader to view this file online. The Reader program can be downloaded **here**.

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Hospital Compliance Letter and Communication Strategy (In Hospital Recommended Protocol for Offering the CBRS)

In an effort to ensure compliance with the new law in Arizona, this letter was sent out by the M.I.S.S. Foundation to local hospitals.

P.O. Box 5333 Peoria, Arizona 85385 623.979.1000 www.missfoundation.org

August 30, 2001

Dear Hospital Administrators and Obstetrical Department Directors,

"We all know this is a change that is long overdue." With those simple words, Governor Jane Dee Hull picked up her pen and signed into law House Bill 2416, also known as The Missing Angels Bill. Effective August 9, 2001, the Office of Vital Records and Statistics of the Arizona Department of Public Health will begin issuing "Certificates of Birth Resulting in Stillbirth" to parents of stillborn infants. By statute the certificate must be offered to them at the hospital. The law is retroactive and will include infants born still prior to the enactment of the law. Arizona is the first state in the U.S. to change this law.

Because this new law was effective August 9, 2001, hospitals should begin informing parents of stillborn infants of the opportunity to have the stillbirth recorded in the same manner as live births are recorded. It is not mandatory for the hospital to complete the new form if the parents decline but it is mandatory that it be offered to them. This new form enables the parents to receive a CERTIFICATE OF BIRTH RESULTING IN STILLBIRTH. Enclosed is a suggested script your staff may want to use when discussing this with parents.

The change in the law came about because the M.I.S.S. Foundation cared that women - some of whom carried their babies to term and beyond - were being denied recognition of their birthing event because their baby was born still. The physical pain for these mothers was no less, but the emotional pain was overwhelming. A piece of paper is a poor substitute for a baby, but it is tangible evidence that they did give birth and that their baby, though not living, still matters. If you are interested in an informational workshop to teach your employees about the new law, the MISS Foundation offers this training based on your available budget. Please contact me at 623.979.1000 if you would like more information.

Very Sincerely Yours,

Joanne Cacciatore-Garard

Founder and Director, M.I.S.S. Foundation

Enclosures

cc: Laurie Lange, V.P., Public Affairs - Arizona Hospital and Healthcare Association

FOR MEDICAL PROFESSIONALS

Suggested script for ATTENDING NURSE/PHYSICIAN for the implementation of HB2416—Legislation clearly states that families **must be offered** the certificate at the time of their stillborn child's birth:

Mr. (Mrs.) Olsen,

We are all so very sorry that your baby died. There simply are no words to express the depth of your sorrow. We are here to try to help you through this overwhelming time. I

know it must come as a terrible shock to you.

In the days ahead there will be some details you will need to take care of and Ms. (Mr.) Name. Our social worker will help you with some of those, however, there is one detail you may be able to take care of now.

Even though your baby (USE CHILD'S NAME) was not breathing at the time of his (her) birth, we can report that your child's birth occurred so that when you're ready, you can apply for a Certificate of Birth for your baby. Unlike the regular Certificate of Live Birth this one will show that your baby was "stillborn". Other than that its like any other birth certificate.

You may choose never to apply for a copy but if you do then at least the information will be there. There is no charge for us to prepare the report.

Would you like us to complete Hailey's (CHILD'S NAME) Certificate of Birth form for you?

For more information, contact Joanne Cacciatore, The M.I.S.S. Foundation, 623.979.1000 or visit our bilingual webpage at www.missfoundation.org.

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The **M.I.S.S. Foundation** is a nonprofit, 501(c)3, international organization which provides immediate and ongoing support to grieving families, empowerment through community volunteerism opportunities, public policy and legislative education, and programs to reduce infant and toddler death through research and education.